Section 4: Risks for Racial and Ethnic Groups Participating in Genetic Research

I. Stigmatization and Discrimination

*Individual Risks:* Genetic research may yield personal information regarding disease and disability risks, susceptibility to toxins, paternity, and ancestry. This information may be of interest to a wide range of individuals and organizations, including family members, employers, insurers, courts, and the government. If the information is disseminated, discrimination or other harm to research participants might result. While reported cases of genetic discrimination have been limited, they evince a willingness on the part of some employers and insurers to act upon genetic information, often attributing to particular alleles a higher level of risk of disease than might a scientist. Some commentators have stated that the perceived risk of genetic discrimination among the public is significantly greater than the actual risk. Nevertheless, the perceived risk of discrimination has its own effects and has been shown to discourage individuals from seeking predictive genetic testing, as well as from participating in genetic research. Several studies have found that members of racial and ethnic groups with a history of exploitation by medical researchers are particularly concerned about the risk of genetic discrimination.

Rothstein and Anderlik 2001 (pp. 354-358) review research and statements on genetic discrimination. Hudson 1995 (pp. 391-393) discusses the potential for genetic-based insurance discrimination. Miller 1998 (pp. 189-197) discusses the potential for genetic-based employment discrimination. Lapham 1996 (pp. 621-624) presents data on the public’s perceived risk of genetic-based discrimination. Hall and Rich 2000 (pp. 214-221) and Peterson 2002 (pp. 79-87) discuss the effects of this perceived risk on the use of diagnostic genetic tests. Bowman 2000 (pp. 207-212) discusses the specific concerns of African Americans about genetic-based discrimination.

*Group Stigmatization and Discrimination:* Because both race/ethnicity and genetics are often imbued with exaggerated degrees of absolutism by the public, genetic findings that link a racial or ethnic population to a disease or disorder risk stigmatizing the group involved. Oversimplified presentations of genetic findings by the media can lead to incorrect understandings about a group’s overall fitness, intelligence, or behavior. Stigmatization can be particularly powerful when the presentation of genetic findings aligns with traditional stereotypes about a group. Research linking racial or ethnic groups to a disease or disorder may also result in discrimination against the group. Where genetic findings communicate the notion that a particular racial or ethnic group is at higher risk for a disease, an occupational injury, or a mental or behavioral disorder, there exists the possibility that insurers, employers or health care providers may decide it is in their best interests to implement policies pertaining to the group generally. Genetic research that offers conclusions about a group’s origins, ancestral composition, or genetic relation to other groups may also lead to cultural harm if those conclusions differ from those already held by the group.

Wolf 1995 (pp. 345-353) and Parrott 2005 (pp. 980-990) review the risk of group discrimination and stigmatization from genetic research. Nelkin 2002 (pp. 121-132) examines past cases of genetic stigmatization. Davis 2004 (pp. 40-49) and Elliot and Brodwin 2002 (pp. 1469-1471) overview the issues that arise for groups when genetic research reflects on identity.
II. Privacy and Confidentiality
Researchers collecting genetic information are subject to the confidentiality requirements of the Common Rule, which applies to federally funded research and to research under the auspices of institutions that have adopted the rule more broadly. In addition, some research projects are covered by privacy regulations issued under the Health Insurance Portability and Accountability Act (HIPAA). However, the Common Rule provides only a loose framework for regulation of confidentiality: “When appropriate, there are [to be] adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data.” In addition, the HIPAA regulations only cover researchers when they are seeking information from a health care provider or plan or when they themselves are providing health care. Most states have taken steps to provide enhanced protections for genetic information. However, states differ greatly in the amount of protection they provide. As a result, a number of racial and ethnic groups have expressed concern about the confidentiality of genetic information, advocating the implementation of additional protections including prohibiting the secondary use of genetic information and destroying samples at the conclusion of a study. Stored samples present particular problems in that they are often attached to personal information, such as race and ethnicity. As a result, even if samples are stripped of identifiers, their use may still enable researchers to link findings to particular racial or ethnic groups. There has been little effort to regulate or standardize such identifiers among DNA banks.

Anderlik and Rothstein 2001 (pp. 401-433) and Fuller 1999 (pp. 1359-1361) provide reviews of recent writing and research on genetic privacy.
Common Rule, 46 C.F.R. Sec 101ff, codifies the federal rules dealing with human experimentation.
Standards for Privacy of Identifiable Health Information, 45 C.F.R. Secs. 160 and 164, contains the HIPAA privacy regulations.
National Conference of State Legislatures 2006 presents a study of the ways different states treat genetic privacy.
Wang 2001 (pp. 18-26) and Wong 2004 (pp. 44-54) describe the concerns of specific racial and ethnic groups regarding genetic privacy.
Deschenes 2001 (pp. 145-178) and Anderlik 2003 (pp. 203-215) examine genetic privacy in regard to DNA banks.

III. Reification of Race/Ethnicity
Opponents of the use of racial and ethnic categories in genetic research have voiced concern that such use results in the reification of the categories within biomedical research, the health care system, and society more broadly. Many genetic researchers have stated that the use of racial and ethnic categories represent a way station in the progression of genetic research towards personalized medicine and that once the ability exists to diagnosis and treat disease based solely upon an individual’s genotype the need to use racial and ethnic categories will disappear. However, it has also been argued that as the use of racial and ethnic categories in genetic research and the development of race-specific therapies, such as BiDil, reinforce the biological significance of race and ethnicity in certain diseases, the use of race and ethnicity in research and in clinical care will increase. Some researchers and social scientists have also voiced concern that as the public hears that race and ethnicity are biologically meaningful in regard to an ever-lengthening list of diseases, it will conclude that race and ethnicity are equally
meaningful with regard to intelligence, behavior, and morality. From this point, they suggest that it is but a small step to the support of public and private policies that discriminate on the basis of race and ethnicity. Suggestions that there may exist an intelligence-gene or a violence-gene that can explain lower test scores and higher rates of violent crime in certain racial and ethnic groups have already been made, and while most genetic researchers disclaim the existence of such genes, they are hard-pressed to counter the success of their own competing message, that genetics has the ability to explain the intricacies of the human body and mind.

Juengst 2004 (pp. 267-275) and Ossorio and Duster 2005 (pp. 115-128) overview the issue of racial/ethnic reification.

Collins 2004 (pp. S13-S15) and Rothstein and Epps 2001 (pp. 104-108) argue that the use of race/ethnicity in genetic research is a temporary step towards personalized medicine.

Lee 2005 (pp. 2133-2138) argues that commercial factors will prolong use of race in medical research.

Marks 2005 (pp. 13-16) and Schwartz 2001 (pp. 1392-1393) discuss the effect of using racial and ethnic categories in genetic research on their use in clinical care.

Duster 2005 (pp. 1050-1051) and Rotimi 2004 (pp. S43-S47) overview the possibility that the use of racial and ethnic will reify public conceptions of race.

Condit 2004 (pp. 402-408) and Nelkin 2001 (pp. 555-559) examine how the media communicates genetic findings about race and ethnicity to the public.

Newson and Williamson 1999 (pp. 327-342) overviews calls to undertake genetic research on intelligence.

Rothstein 2005 (pp. 793-798) overviews calls to undertake genetic research on behavior.

IV. Case Study: African Americans and Sickle Cell Disease

Soon after its initial description in 1910, sickle cell disease became firmly understood within the medical community as a racial disease, specifically one unique to African Americans. “Sickle cell anemia,” Thomas Cooley observed in 1928, “is distinctly racial and possibly originally limited to a small section of the negro race.” Although cases of the disease had also been documented among patients who were not identified as African American, the disease had become so closely linked to that population that physicians responded to these cases by questioning either the accuracy of the diagnosis or of the racial identity of the patient. So too, ideas about race were determinative in the 1940s when investigators distinguished the sickle cell trait from sickle cell anemia. Sickle cell trait appeared more common among Africans living in Africa than among African Americans, yet sickle cell anemia was described almost exclusively in African Americans. To explain this phenomenon, investigators hypothesized that admixture with white people had weakened the biological and genetic constitution of African Americans. “The hybrid American Negro suffering from sickle cell anemia was living proof…of the dysgenic effects of race-mixing.”

In the aftermath of the Civil Rights movement, President Richard Nixon proposed a five-fold increase in sickle cell research funding and in 1972, Congress passed the National Sickle Cell Anemia Control Act. Some groups, including the Black Panthers and the Black Athletes Foundation for Sickle Cell Anemia, quickly organized community-based screening programs. However, others, fearful that the screening programs had genocidal and/or eugenic implications, discouraged participation in them. Why, asked some community members, was the legislation entitled the “National Sickle Cell Anemia Control Act,” and not the “National Sickle Cell Anemia Prevention Act?”
The federal legislation itself, as well as some state legislation and screening programs, failed to distinguish between sickle cell trait and sickle cell disease. As a result, many participants who were carriers were erroneously informed that they had the disease. This led to gross overestimates of prevalence, which contributed to the stigmatization of carriers and promoted discrimination against them. Some carriers were charged higher insurance premiums or denied health insurance and life insurance. Others were refused jobs or fired as result of their carrier status, on the assumption that carrier status reduced a person’s ability to fulfill job requirements. For example, the U.S. Air Force at times refused to accept carriers into the service and at other times, restricted the duties assigned to them.

These developments created within African American communities tensions that were, in turn, exacerbated by other errors and misrepresentations. People were erroneously informed that an individual with sickle cell disease would likely die by age twenty. Moreover, screening programs were often designed exclusively for African Americans. In order to obtain a New York state marriage license, all persons “not of the Caucasian, Indian, or Oriental races” had to undergo testing for sickle cell. Negative attitudes were reinforced when some legislation labeled sickle cell “communicable,” as though it were an infectious disease. Finally, acceptance of research and screening for sickle cell was further reduced by a lack of public education and genetic counseling.

Lessin and Jensen 1974 (pp. 529-532) present the history of research on sickle cell. Wailoo 1991 (pp. 185-208) and Tapper 1997 (pp. 263-289) examine how early researchers linked the disease to race. Tapper 1999 (pp.) and Matarasso 1980 (pp. 650-655) examine how sickle cell became a significant social concern in the 1970s. Manley 1984 (pp. 67-71) and Reilly 1975 (pp. 319-76) review the federal and state sickle cell legislation that was passed in the 1970s. Pearson and O’Brien 1972 (pp. 1201-1204), Powledge 1973 (pp. 38-47) discuss the implementation of sickle cell screening programs and the related controversy that ensued. Severo 1980 (pp. 243-245) and Markel 1998 (pp. 161-176) discuss the cases of discrimination that occurred as a result of misinformation about sickle cell, and how these cases were viewed by the African American community.